

# The Impact of Parental Stress among the Quality of Life of mothers of children with Autism Spectrum Disorder and Down Syndrome

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## HOW TO CITE:

Turda, E. S. (2023).

The Impact of Parental Stress among the Quality of Life of mothers of children with Autism Spectrum Disorder and Down Syndrome. *International Journal of Special Education*, 38(3), 95-106.

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## DOI:

<https://doi.org/10.52291/ijse.2023.38.42>

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## ABSTRACT:

For most parents, the birth of their child is a reason for joy because the child is the center of their Universe. He is light, hope, smile, change, and future. Raising a child with a disability can have a profound impact on the family. This causes great stress for parents, especially for the mother. Prolonged stress negatively influences their quality of life, causing health problems and having a high level of fatigue, anxiety, and depression.

This research aimed to investigate the level of parental stress among mothers of children with autism spectrum disorder respectively, among mothers of children with Down syndrome.

The results of this study demonstrated significant differences regarding the measured variables among mothers of children with ASD and Down syndrome. Regarding coping mechanisms, mothers of children with ASD use religious coping more frequently compared to mothers of children with Down syndrome, who use the following coping mechanisms: active coping, planning, seeking instrumental support, seeking emotional support, acceptance, mental disengagement, and venting. Additionally, the level of parental stress is higher among mothers of children with ASD, and their quality of life is lower; the tendency of social isolation is at a fairly high level.

**Keywords:** ASD, coping mechanisms, Down Syndrome, parental stress, quality of life

## INTRODUCTION

The crisis generated upon receiving the diagnosis is the most difficult experience in a parent's life. Parents are usually stuck when the newborn has problems, and it usually takes them about two years to recover from the initial disappointment or depression. In contrast, other parents continue the process of "grieving" after the baby who hoped to have him all his life. This process of adaptation and acceptance can lead to maladaptive coping methods, such as waiting for the discovery of a miracle drug, overprotection of the child, ambivalence, and infantilization. Also, during this period, there is an increased risk of parents' health problems (depression, anxiety) (Scherer et al., 2019).

Autism spectrum disorder respectively Down's syndrome are lifelong diagnoses. Still, they can be improved through therapeutic intervention as early as possible and primarily through parents' direct and indirect involvement in the therapeutic approach. For this, in the family dynamics of a child with autism and Down syndrome, there must be several situational aspects: the presence of low-stress levels and active coping mechanisms.

Quality of life involves indicators such as good health, adequate housing, employment, personal and family security, education and recreation, mental health, physical health, adequate family life, social life, job security and freedom (Sadeghi et al., 2013). Quality of life is a broad concept that includes notions such as physical and psychological health conditions, level of independence, quality of social relationships (Bayatiani et al., 2011), and connection with critical environmental aspects.

## THEORETICAL FRAMEWORK

A parent with a child with developmental disabilities can be a significant source of stress. Some research (Crnic et al., 2017; Hauser-Cram et al., 2013; Hsiao, 2018; Paster et al., 2009) has shown that the stress level of a parent whose child has some developmental issues is higher compared to that of the parent of the child with a typical course of development.

Sharpley et al. (1997) believe that the most significant sources of stress experienced by parents of children with pervasive developmental disorders are:

1. Perpetuation of the condition;
2. Disapproval of the child's behavior by society;
3. Social support is not provided.

A child diagnosed with autism spectrum disorder can be a constant source of stress for the family, mainly affect-

ing their mothers, siblings, and relationships with other family members (Sanders & Morgan, 1997).

It is very common for both mothers and the entire family of the child with ASD to feel helplessness, feelings of failure, anger, guilt, frustration, and resentment (Jones, 1997). It has been shown that the level of parental stress of mothers of children with ASD is positively correlated with the child's emotional and behavioral level (Bitsika & Sharpley, 2017; Clauser et al., 2021; Tomeny, 2017; Yorke et al., 2018) and negatively correlated with the child's ability to verbalize functionally (Stanojević et al., 2017), limiting their freedom and ability to engage in other social activities over time (Higgins et al., 2005). There are researchers (Rodrigue et al., 1990; Benson & Dewey, 2008; Gika et al., 2012) who demonstrated in their studies that stress was associated with the impact of their child's autism spectrum disorder with the following aspects of life family: recreational activities, household activities, mental and emotional health of members, marital relationship and relationships with other family members, friends and/or neighbors.

Additionally, reviewing the Down syndrome literature, mothers of children with Down syndrome reported a low level of stress, had a satisfactory level of social support, and perceived their child as one without any degree of difficulty (Abbeduto et al., 2004; Esbensen & Seltzer, 2011). They also report low levels of pessimism about their child's future and low levels of depression (Esbensen & Seltzer, 2011).

Pastor-Cerezuela et al. (2021) conducted a study on a sample of 97 parents whose aim was to compare the level of parental stress and resilience of parents with children with autism spectrum disorder (ASD), Down syndrome (DS), and typical development (TD). The results showed that parents of children with Down Syndrome have a low level of stress and an increased level of resilience compared to parents of children with ASD. These results are consistent with the conclusions of other studies (for example, Ahammed, 2021; Giallo et al., 2013; Halstead et al., 2018; Marchal et al., 2016).

The stress of raising children is a factor to consider when providing services to the family. For example, Boyd (2002) showed that there are three main factors associated with the education of the child with autism; these factors are concern for the permanence of the disability, poor acceptance of the child with autism by society and by the other family members, and the low level of social support received by the parents. Stress and depression are the two main factors that lead mothers of autistic children to social isolation.

### ***The role of social support and coping mechanisms in reducing the level of parental stress***

Social support is a way of adaptation because it produces emotional mastery, can lead you to other ways of seeing and adapting to the problem, and provides feedback on a specific behavior. The social network of the family can be formal or informal; an example of a standard social network can be work colleagues or neighbors and, at an informal level, family and friends.

Woolfson (2004) brings into discussion the social implications of a person with disabilities, dealing with such topics as medical problems, disability as a tragedy, and the barriers that underlie the independence of the person with disabilities; all this, in his opinion, can lead to the social isolation of the family.

Woolfson (2004) describes feelings of pity that friends or close families show to families of children with disabilities and concludes that most parents reject such feelings precisely because they desire to maintain a positive point of view that helps children in their integration as community members. These efforts led to correcting society's negative views towards these children and treating them with equal rights to typical children.

Faced with stressful situations, the individual has developed specific mechanisms to cope with stress. These mechanisms act either preventively, in the sense of modifying or annihilating negative effects, or adaptively, to reduce distress if it has already been induced. To define these mechanisms of prevention and adaptation to stress, Lazarus (1991) (as cited in Miclea, 1997) introduces the term coping, defined as "any mechanism of prevention or adaptation to stress, any transaction between the subject and the environment in order to reduce the intensity stress" (p. 10). According to how the individual focuses his attention on the problem that has arisen or on his own emotion generated by the respective problem, three types of coping are distinguished (Suls & Fletcher, 1985 as cited in Miclea, 1997): problem-centered coping, emotion-centered coping, re-evaluation of the problem. The first form of coping is used when potentially reversible situations generate mental stress; within this form of coping, the individual undertakes a series of activities such as evoking previous experience (possible successes in the same situation), counting on social support, requesting information and looking for means of action.

Instead, coping styles are viewed as dispositional variables that refer to the relatively stable characteristics of an individual. The results of some studies conducted on different groups (Endler & Parker, 1990; Higgins & Endler, 1995; Cohan et al., 2006) indicated that emotion-orient-

ed coping style (e.g., self-blame) correlates positively with specific problems of health such as depression, anxiety, and somatic disorders, while the task-oriented style (active approach in solving problems) correlates negatively with the conditions of carrying out a task.

According to Hastings and Johnson (2001), coping mechanisms affect the level of parental stress, and the relationship between coping styles and parental stress is not adequately explained. Smith et al. (2008) concluded that the well-being of mothers of children with autism spectrum disorder was associated with a lower level of emotion-focused coping style and a higher level of problem-focused coping style.

Moreover, Tarakeswahr and Pargament (2001) suggest that a high level of parental stress is associated with religious coping. On the other hand, a low level of stress is associated with providing informal support (Hasting & Johnson, 2001), problem-oriented coping (Noojin & Wallander, 1997; Lustig, 2002), and coping focused on family cooperation and integration (Jones & Passey, 2004).

### ***Quality of life of families of children with disabilities***

Burcu and Burcu (2005) define the quality of life starting from an equation:  $QL = 3ME + Ni + 9TF + Am + 4DV$ , where CL – the quality of life represents the sum of all factors with the following meaning:

- (3ME) is the defining factor for the existential mission according to its specifically human condition. Contemporary man has a threefold duty in this world: 1) to perfect himself by giving course to the desired cosmic evolution of all forms of life; 2) to support the other beings (from the human kingdom or other kingdoms) co-participating in the planetary symbiosis, in the processes of their development and 3) to play the stage role received in this world, in social reality, through the program of individual destiny and with the support of the forces divine.
- (Ni) represents the individual nature of the human being, i.e., that internal structure of the psychic system that contains all the particular and defining elements for the individual identity of a specific being. Giving expression to his individual nature in the external environment, the human being feels authentically free, fully updated, or, as we would say, more simply fulfilled.
- (9TF) indicates the 9 activated fundamental needs categories (out of a total of 12) of the Maslow-Delphy pyramid grid: 1-physiological, 2-safety, 3-environmental, 4-social, 5-knowledge, 6- personal valori-

zation, 7-creative, 8-personal identity and respectively 9-spiritual.

- (Am) adaptation to the environment is the managerial factor that guarantees access to the necessary resources by learning and adopting the most effective ways/strategies of existence within the limits of a particular reality at a given time (practically an existential environment) and of "hunting" resources (finding ways to access these resources, through the multitude of obstacles, blockages, etc.). (Am) is the factor of navigation of efficient management.
- 4DV represents the four dimensions of human life in the world. Contemporary man is a being of particular complexity; for growth and development (as a being and as a person), he needs a multitude of resources, which must be specific (adapted) not only quantitatively but also qualitatively, i.e., to come from certain dimensions of existence. These four significant dimensions are as follows:
  - a) *material life*: - including the relationships and actions of the human being that tend to actualize primary needs. Thus, here will be included the chapters of life aimed at, for example, the acquisition of goods (houses, cars, tools, objects, etc.); investments; business; profession and workplace; everything related to wealth and property.
  - b) *social life*: - it includes all the aspects through which man relates to the environment in which he lives and his cohabiting beings. It mainly aims at satisfying the Needs on levels 4, 5, and 6, i.e., sociability, communion, giving and receiving affection, integration and belonging, communication, investigation, discovery, knowledge, freedom, horizon, valorization, and dignity/self-esteem. The capital of social life also includes the opinions, beliefs, individual outlook on life, currents, doctrines, rituals, and practices (not only religious) that the human person shares, regardless of whether they externalize/manifest them publicly to a greater extent smaller.
  - c) *private life*: - includes all aspects (experiences, thoughts, actions, phenomena, undertakings, etc.) through which the human being relates to himself, to discover and know himself, to find his true identity, as well as his place and purpose in the universe, as well as the meaning of the entire existence of everything he encounters in his life.
  - d) *spiritual life*: - reflects the relationships of the human being with the deep meanings of the present reality, with what stands behind things and makes possible the existence and manifestation of all that is.

This research aimed to identify the level of parental stress among mothers of children with autism spectrum disorder respectively, among mothers of children with Down syndrome.

The hypothesis from which this research started are the following:

**Hypothesis 1:** There is a negative correlation between the coping mechanisms (active coping, planning, suppression of competing, restraint, seeking social support, seeking emotional support, positive reinterpretation, acceptance, denial, venting, religion, mental disengagement) adopted by the mothers participating in this study and the level of stress.

**Hypothesis 2:** Mothers of children with autism have a high level of stress respectively a low level of quality of life compared to mothers of children with Down syndrome.

## METHODOLOGY

### *Design*

In order to test the degree of correlation between variables and compare the means between subjects, this pilot study had a correlational and quasi-experimental design. The independent label variable is the gender of the participants, parental stress (measured with the Parental Stress Scale, Berry & Jones, 1995), coping mechanisms (measured with the COPE Questionnaire; Carver et al., 1989), and quality of family life (measured with the Quality of Family Life Questionnaire; Hoffman et al., 2006) are the dependent variables of this study. IBM SPSS Statistics .21 was used for data entry and analysis.

### *Participants*

The participants of this study were 40 mothers of children diagnosed with ASD and Down syndrome, children aged between 6-14 years, from Sighetu-Marmației, Maramureș county, Romania (see Table 1).

We observe that, out of the total of 40 participants, 20 (50%) are mothers whose children are diagnosed with autism spectrum disorder, of which 18 (45%) are boys and 2 (5%) are girls, and 20 (50%) are mothers whose children are diagnosed with Down syndrome, of which 10 (25%) are boys and 10 (25%) are girls. Also, from the total of 20 children with autism spectrum disorder, 13 (32.5%) belong to the age group 6-9 years, and 7 (17.5%) belong to the age group 10-14 years, instead of the 20 children with Down syndrome, 12 (30%) are in the age range 6-9 years and 8 (20%) belong to the age group 10-14 years.

Table 1: Distribution of study participants by gender and age of children

			Age		Total
			6-9 years	10-14 years	
mother	of children with Down Syndrome	Count	12	8	20
		% within mother	60.0%	40.0%	100.0%
	of children with ASD	Count	13	7	20
		% within mother	65.0%	35.0%	100.0%
Total		Count	25	15	40
		% within mother	62.5%	37.5%	100.0%

### Measures

#### *The COPE Inventory (Carver et al., 1989)*

The questionnaire integrates the stress model developed by Lazarus and Folkman (1984). Still, the authors of the questionnaire consider the division of coping forms into two types (problem-focused and emotion-focused) too simplistic. The questionnaire includes 54 statements, scored on a Likert scale from 1 to 4, where 1 means "I usually do not do this", and 4 "I usually do this". The items of the COPE questionnaire are divided into the following 14 scales: active coping, planning, mental disengagement/self-distraction, suppression of competing activities, seeking instrumental support, seeking emotional support, positive reframing, acceptance, denial, restraint, orientation towards religion, venting, behavioral disengagement, and substance use.

The internal consistency coefficient of the scales is between .92 and .62, and that of test-retest reliability is between .83 and .48 (Carver et al., 1989).

#### *Parental Stress Scale (Berry & Jones, 1995)*

The Parental Stress Scale comprises 18 items and is suitable for both mothers and fathers of children with or without clinical problems. This scale represents an alternative to the Parental Stress Index (PSI; Abidin, 1986). To test the validity of this scale, Berry and Jones (1995) compared the Perceived Stress Scale (Cohen et al., 1983) and the PSI (Abidin, 1986), thus obtaining a Cronbach's alpha coefficient of .72. This questionnaire measures the level of parental stress related to low levels of parental sensitivity related to the child, dysfunctional child behavior and lower quality of the child-parent relationship.

Costea-Bărlutiu and coauthors (2014) reapplied and revalidated the parental stress scale applied to parents of children with ASD and Down syndrome from Romania and obtained a Cronbach's alpha coefficient of .83.

#### *Family Quality of Life Scale (Hoffman et al., 2006)*

This questionnaire determines the degree to which the quality of family life is pleasant, supported by the types of resources that are important to family members, as well as the family's barriers.

The questionnaire includes 25 items rated on a Likert scale from 1 to 5, where 1 = "I am totally dissatisfied" and 5 = "I am totally satisfied". These items are divided according to the following 5 areas specific to family life: 1) social interaction; 2) parenting; 3) emotional well-being; 4) material well-being, and 5) social support

High internal consistency of the items was found, the Cronbach  $\alpha$  coefficient being .96 for the entire questionnaire, being adapted for the Spanish population (Verdugo et al., 2005), and for the subscales, it differs .54 for social interaction, .66 for parenting, .70 for emotional well-being, .42 for material well-being, and .77 for social support (Poston et al., 2003).

### Procedure

To begin with, the purpose of applying these scales will be explained. Then, the participants included in the study will be informed about the instructions for completing the scales and signing the informed consent regarding the confidentiality of the answers. The scales will be completed individually on pencil paper, and the time allocated for completion will not be limited.

For the first hypothesis of the study, to test the existence of a correlation between the variables, we used the correlation coefficient  $r$  Pearson because it respects the conditions of use (the two variables are quantitative, and the distribution is normal), and for the second hypothesis of the study to test whether there are differences between the mothers of children with ASD and the mothers of children with Down syndrome at the level of the measured variables, the t-test for independent samples was calculated.

**FINDINGS**

According to Table 1, it can be mentioned the existence of significant differences regarding the use of coping mechanisms by the mothers of children with ASD and Down syndrome. The most frequent coping mechanism of mothers of children with ASD is religious coping (M=3.62); for them, diving into religion

and placing hope in God is a valuable source of peace. Instead, mothers of children with Down syndrome frequently use the following coping mechanisms: active coping (M=3.65), planning (M=3.50), seeking instrumental support (M=3.40), seeking emotional support (M=3.15), acceptance (M=3.61), mental disengagement (M=2.31) and venting (M=2.73) which reduce their level of stress.

Table 2. Descriptive analysis of the results obtained at the level of coping mechanisms

<i>Coping mechanism</i>		<i>Mother with children with Down Syndrome</i>	<i>Mother with children with ASD</i>
<i>Active coping</i>	N	20	20
	Mean	3,65	2,88
	Minimum	3,25	1,75
	Maximum	4,00	4,00
	Std. Deviation	.23	.71
	% of Total Sum	55,8%	44,2%
<i>Planning</i>	N	20	20
	Mean	3,50	2,90
	Minimum	3,00	1,75
	Maximum	4,00	4,00
	Std. Deviation	.34	.71
	% of Total Sum	54,7%	45,3%
<i>Suppression of competing</i>	N	20	20
	Mean	3,17	2,88
	Minimum	2,50	2,00
	Maximum	4,50	4,00
	Std. Deviation	.56	.56
	% of Total Sum	52,4%	47,6%
<i>Restraint</i>	N	20	20
	Mean	3,05	2,66
	Minimum	2,50	1,75
	Maximum	4,00	3,75
	Std. Deviation	.53	.60
	% of Total Sum	53,4%	46,6%
<i>Seeking instrumental support</i>	N	20	20
	Mean	3,40	2,98
	Minimum	3,25	1,75
	Maximum	4,00	4,00
	Std. Deviation	.23	.66
	% of Total Sum	53,2%	46,8%

<i>Seeking emotional support</i>	N	20	20
	Mean	3,15	2,55
	Minimum	2,25	1,50
	Maximum	4,00	4,00
	Std. Deviation	.52	.83
	% of Total Sum	55,3%	44,7%
<i>Positive Reinterpretation</i>	N	20	20
	Mean	3,21	3,03
	Minimum	2,25	2,00
	Maximum	4,00	4,00
	Std. Deviation	.60	.62
	% of Total Sum	51,4%	48,6%
<i>Acceptance</i>	N	20	20
	Mean	3,61	2,96
	Minimum	3,25	1,50
	Maximum	4,50	4,00
	Std. Deviation	.30	.73
	% of Total Sum	54,9%	45,1%
<i>Denial</i>	N	20	20
	Mean	2,33	2,21
	Minimum	1,50	1,25
	Maximum	3,00	3,25
	Std. Deviation	.64	.57
	% of Total Sum	51,4%	48,6%
<i>Religion</i>	N	20	20
	Mean	3,51	3,62
	Minimum	2,75	2,50
	Maximum	4,00	4,00
	Std. Deviation	.49	.45
	% of Total Sum	49,2%	50,8%
<i>Mental disengagement</i>	N	20	20
	Mean	2,31	2,15
	Minimum	1,50	1,25
	Maximum	3,50	3,00
	Std. Deviation	.79	.44
	% of Total Sum	51,8%	48,2%
<i>Venting</i>	N	20	20
	Mean	2,73	2,53
	Minimum	2,50	1,50
	Maximum	3,25	3,75
	Std. Deviation	.32	.62
	% of Total Sum	51,9%	48,1%

Table 3. The correlation coefficients of the measured variables

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Parental stress	-												
2. Active coping	.10	-											
3. Planning	-.07	.84**	-										
4. Suppression of competing	.23	.71**	.48**	-									
5. Restraint	.21	.71**	.47**	.81**	-								
6. Seeking instrumental support	.02	.77**	.75**	.70**	.63**	-							
7. Seeking emotional support	-.24	.48**	.50**	.46**	.41**	.77**	-						
8. Positive reinterpretation	-.15	.56**	.51**	.66**	.51**	.72**	.72**	-					
9. Acceptance	.09	.77**	.62**	.69**	.64**	.70**	.54**	.66**	-				
10. Denial	.08	-.16	-.24	.08	.29	-.05	-.02	-.25	.006	-			
11. Religion	.48**	-.13	-.12	-.03	.06	-.03	-.22	-.37*	-.15	.52**	-		
12. Mental disengagement	.37*	.10	-.16	.50**	.51**	.17	.18	.22	.21	.43**	.26	-	
13. Venting	-.17	.25	.36*	.14	.17	.47**	.43**	.07	.11	.31*	.08	-.16	-

\*\* Correlation is significant at the .01 level (2-tailed); \* Correlation is significant at the .05 level (2-tailed)

Calculating the Pearson r correlation coefficient for the first hypothesis (see Table 3), we observe a significant positive correlation between parental stress and the religious-oriented coping mechanism  $r_{(38)}=.48, p<0.01$ , and the mental disengagement coping mechanism  $r_{(38)}=.37, p<0.05$ , which means that there is a moderate association between the two variables. However, between coping mechanisms planning  $r_{(38)} = -.07$ ; seeking emotional support  $r_{(38)} = -.24$ , positive reinterpretation  $r_{(38)} = -.15$ , venting  $r_{(38)} = -.17$ , and parental stress, there is a statistically insignificant correlation. Therefore, the first hypothesis is not confirmed.

Observing Table 4, regarding the level of stress, mothers of children with ASD have a higher level ( $M=3.71$ )

compared to mothers of children with Down syndrome; for them, the primary source of stress is the child, and taking care of him occupies a long time, consuming quite a lot of their energy. Besides these aspects, the child's behavior often causes them to be ashamed and stressed, reducing their flexibility and the level of satisfaction of being a parent. For the variable quality of life, there are significant differences at the level of the subscales. Thus, mothers of children with Down syndrome have a high level of social interaction ( $M=4.30$ ), parenting ( $M=4.41$ ), emotional well-being ( $M=4.13$ ), and social support ( $M=4.21$ ) compared to mothers of children with ASD. According to the obtained results, it is noted that the mothers of children with Down syndrome

Table 4. The results of the t-test for the quality of family life according to the groups participating in the study

Variables	Mothers with children with ASD		Mothers with children with Down Syndrome		t test	df	p
	M	SD	M	SD			
Parental stress	3,71	.34	3,58	.42	1.06*	38	.04
Social interaction	3,34	1.09	4,30	.44	3.61**	38	.00
Parenting	3,56	.87	4,41	.58	3.60	38	.10
Emotional well-being	3,30	.78	4,13	.71	3.65	38	.75
Social support	3,85	1.04	4,21	.83	1.21	38	.06

\* $p<.05$  \*\* $p<.01$

enjoy many moments with their family, they have open communication with each other, they have support from family members, they know how to face failures, they focus more on develop the child's autonomy and independence and become more involved in the child's integration and inclusion process. From a statistical point of view, we find that there are significant differences only at the level of parental stress ( $t_{(38)}=1.06$ ;  $p<.05$ ), respectively the social interaction coping mechanism ( $t_{(38)}=3.61$ ;  $p<.01$ ). It seems that in the case of mothers of children with ASD, the tendency to isolate themselves is high, they spend all their time with the child, not taking into account his interests, needs, passions, and some prefer to distance themselves from other family members, without allowing them to get involved in school tasks or the child's therapeutic activities. In conclusion, the second hypothesis is only partially confirmed.

## CONCLUSION

The stress that arises from the child's day-to-day care can influence the parents' health and functioning and their relationships with their children. The stress of the role of parent differs from the other stresses of everyday life related to work and other interpersonal relationships, but they are not totally independent; for example, parental stress is closely related to marital conflicts. It is associated with the development and adaptation of the child. Numerous theories of stress have emphasized a causal link between increased parental stress, impairments in various aspects of parental care, and escalation of children's behavioral problems (Deater-Deckard et al., 2005).

The present study investigated the relationship between parental stress, quality of life, and coping mechanisms among mothers of children with autism spectrum disorder and Down syndrome. One of the hypotheses of this research focused on investigating a correlation between parental stress and coping mechanisms. Thus, calculating the Pearson  $r$  correlation coefficient, we observed that there is a significant positive correlation between parental stress, religion coping mechanism  $r_{(38)}= 0.48$ ,  $p<0.01$ , and mental disengagement coping mechanism  $r_{(38)}= 0.37$ ,  $p<0.05$ . In the study conducted by Hastings et al. (2005) they demonstrated that parents of children with autism use as coping mechanisms: active coping, problem-solving coping, religious coping and denial. In addition, the high level of parental stress is among mothers of children with autism ( $M=3.71$ ,  $SD=.34$ ), compared to mothers of children with Down syndrome ( $M=3.58$ ;  $SD=.42$ ). Also, Miranda and coauthors (2019)

demonstrated that coping strategies, behavioral difficulties, and social support are significant predictors between the severity of symptoms and parenting stress in mothers of children with ASD. Similar conclusions emerge from other studies, which focus on the correlation between the behaviors of children with ASD and the level of maternal stress (Ashworth et al., 2019; Lai & Oei, 2014). The results of the study carried out by Lai & Oei (2014) highlighted the fact that due to communication difficulties, low levels of social interaction, and rigid patterns of behavior that often lead to behaviors such as anxiety or obsessive rituals, mothers of children with ASD have an increased level of parental stress due to the difficulty and inability to manage them. Additionally, Ashworth and coauthors (2019) carried out a study on 265 parents of children aged 4-25 years with Williams syndrome, Down syndrome, and ASD, whose purpose was to investigate parental stress in the three categories of diagnoses. The results showed that the level of parental stress was higher in the case of parents of children with ASD, and the severity of the disorder might be a better explanation for this increased level.

The results of the second hypothesis of this research showed that there are significant differences in terms of parental stress, respectively, the quality of life of mothers of children with ASD and Down syndrome. Thus, mothers of children with Down syndrome have a high level of social interaction, parenting, emotional well-being, and social support in comparison with mothers of children with ASD. Similar results were obtained by Oliveira and Limongi (2011) and Abbasi with coauthors (2016), concluding that mothers of children with Down syndrome have an increased quality of life, declaring themselves satisfied with their level of well-being.

One of the limitations of this study could be the small number of participants; due to the limited sample size, there is not a high degree of accuracy in the generalization of the obtained results. The second limitation of this study would be the non-involvement of fathers in the study or the non-integration of an exogenous variable such as marital status. The last limitation could be that questionnaires are not validated and adapted to the Romanian population, so their psychometric properties remain unchanged.

A future research direction could be the development of an intervention program using the methods: training to provide useful information for mothers of children with ASD in terms of parenting and focus groups in which fathers with ASD are also involved to raise awareness of the importance of offering social support to moth-

ers of children diagnosed with autism spectrum disorder. Another future research direction would be to introduce a mediation analysis to test the relationship between mindfulness-well-being-stress levels. Thus, according to this model, mindfulness meditative practices will develop mothers of children with ASD a high level of well-being, which, in turn, will decrease their stress levels.

#### ACKNOWLEDGEMENT

None

#### DECLARATION OF INTEREST STATEMENT

The author reported no potential conflict of interest.

#### FUNDING

None

#### REFERENCES:

- Abbasi, S., Sajedi, F., Hemmati, S., Najafi Fard, T., Azadchehr, M. J., & Poursadoghi, A. (2016). Evaluation of quality of life in mothers of children with Down syndrome. *Journal of Practice in Clinical Psychology*, 4(2), 81-88. <http://dx.doi.org/10.15412/J.JPCP.06040202>
- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, down syndrome, or fragile X syndrome. *American Journal on Mental Retardation*, 109(3), 237-254.
- Abidin, R. R. (1986). *Parenting Stress Index Manual* (2<sup>nd</sup> ed.). Pediatric Psychology Press.
- Ahammed, H. (2021). Quality of Life, Parental Stress & Perceived Social Support Among Parents of Children with Autism Spectrum Disorder. *The International Journal Of Indian Psychology*, 9(2).
- Ashworth, M., Palikara, O., & Van Herwegen, J. (2019). Comparing parental stress of children with neurodevelopmental disorders: The case of Williams syndrome, Down syndrome and autism spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 32(5), 1047-1057. <https://doi.org/10.1111/jar.12594>
- Bayatiani, A., Pour Mohammad Rezaye Tajrishi, M., Gangalivand, N., Mirzamani, M., & Salehi, M. (2011). The relationship between social network and quality of life in parents of students with intellectual disabilities. *Journal of Exceptional Children*, 11(2), 163-174.
- Benson, B., & Dewey, D. (2008). Parental stress and needs in families of children with autism spectrum disorder. *International Journal of Disability, Community & Rehabilitation*, 7(1), 1-9.
- Berry, J. D., & Jones, W. H. (1995) The Parental Stress Scale: initial psychometric evidence. *Journal of Social and Personal Relationships*, 12, 463 – 472.
- Bitsika, V., & Sharpley, C. F. (2017). The association between autism spectrum disorder symptoms in high-functioning male adolescents and their mothers' anxiety and depression. *Journal of Developmental and Physical Disabilities*, 29, 461-473. <https://doi.org/10.1007/s10882-017-9537-1>
- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 17(4), 208-215.
- Burcu, A., & Burcu, A. (2005). *Aspecte privind conceptul și managementul calității vieții. Factori determinanți ai calității vieții* [Aspects of the concept and management of quality of life. Determinants of quality of life]. București: Argonaut.
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56, 267-283.
- Clauser, P., Ding, Y., Chen, E. C., Cho, S. J., Wang, C., & Hwang, J. (2021). Parenting styles, parenting stress, and behavioral outcomes in children with autism. *School Psychology International*, 42(1), 33-56. <https://doi.org/10.1177/0143034320971675>
- Cohan S. L., Jang K. L., & Stein M. B. (2006) Confirmatory factor analysis of a Short Form of the Coping Inventory for Stressful Situations. *Journal of Clinical Psychology*, 62, 273-83.
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24(4), 385-396.
- Costea-Bărluțiu, C., Bălaș-Baconschi, C., & Hathazi, A. (2014). A Preliminary Investigation of a Parental Stress Measure for Parents of Children With Autism Spectrum Disorders and Down Syndrome, *Studia Universitatis Babeș-Bolyai*, 2, 25-40.

- Crnice, K. A., Neece, C. L., McIntyre, L. L., Blacher, J., & Baker, B. L. (2017). Intellectual disability and developmental risk: Promoting intervention to improve child and family well-being. *Child development*, 88(2), 436-445. <https://doi.org/10.1111/cdev.12740>
- Deater-Deckard, K., Smith, J., Ivy, L., & Petril, S. A. (2005). Differential perceptions of and feelings about sibling children: Implications for research on parenting stress. *Infant and Child Development*, 14(2), 211-225.
- Endler, N. S., & Parker, J. D. A. (1990). Coping Inventory for Stressful Situation. Manual. Toronto: Multi-Health Systems.
- Esbensen, A. J., & Seltzer, M. M. (2011). Accounting for the "Down syndrome advantage". *American Journal of Intellectual and Developmental Disabilities*, 116(1), 3-15.
- Giallo, R., Wood, C. E., Jellett, R., & Porter, R. (2013). Fatigue, wellbeing and parental self-efficacy in mothers of children with an autism spectrum disorder. *Autism*, 17(4), 465-480. <https://doi.org/10.1177/136236131311416830>
- Gika, D. M., Artemiadis, A. K., Alexopoulos, E. C., Daviri, C., Papanikolaou, K., & Chrousos, G. P. (2012). Use of a Relaxation Technique by Mothers of Children with Autism: A Case-Series Study. *Psychological Reports*, 111(3), 797-804. <https://doi.org/10.2466/20.15.21.PR0.111.6.797-804>
- Halstead, E., Ekas, N., Hastings, R. P., & Griffith, G. M. (2018). Associations between resilience and the well-being of mothers of children with autism spectrum disorder and other developmental disabilities. *Journal of Autism and Developmental Disorders*, 48(4), 1108-1121. <https://doi.org/10.1007/s10803-017-3447-z>
- Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of autism and developmental disorders*, 31(3), 327-336.
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Degli Espinosa, F., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9(4), 377-391.
- Hauser-Cram, P., Cannarella, A., Tillinger, M., & Woodman, A. C. (2013). Disabilities and development. In R. M. Lerner, A. Easterbrooks, and J. Mistry (Eds.), *Handbook of psychology, Vol. 6: Developmental psychology* (2nd ed.), (pp. 547-570). Hoboken, NJ: Wiley.
- Higgins J. E., & Endler N. S. (1995) Coping, life stress, and psychological and somatic distress. *European Journal of Personality*, 9, 253-70.
- Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9(2), 125-137.
- Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the beach center family quality of life scale. *Journal of Marriage and Family*, 68(4), 1069-1083.
- Hsiao, Y.-J. (2018). Parental Stress in Families of Children With Disabilities. *Intervention in School and Clinic*, 53(4), 201-205. <https://doi.org/10.1177/1053451217712956>
- Jones, G. (1997). Disabling Children: Autism, the Effect on Families and Professionals, *Educational and Child Psychology*, 14(3), 71-76.
- Jones, J., & Passey, J. (2004). Family adaptation, coping and resources: Parents of children with developmental disabilities and behaviour problems. *Journal on developmental disabilities*, 11(1), 31-46.
- Lai, W. W., & Oei, T. P. S. (2014). Coping in parents and caregivers of children with autism spectrum disorders (ASD): A review. *Review Journal of Autism and Developmental Disorders*, 1, 207-224. <https://doi.org/10.1007/s40489-014-0021-x>
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NJ: Springer.
- Lazarus, R. S. (1991). *Emotion and Adaptation*. Oxford: Oxford University Press.
- Lustig, D. C. (2002). Family coping in families with a child with a disability. *Education and Training in Mental Retardation and Developmental Disabilities*, 37(1), 14-22.
- Marchal, J. P., Maurice-Stam, H., van Trotsenburg, A. P., & Grootenhuis, M. A. (2016). Mothers and fathers of young Dutch adolescents with Down syndrome: Health related quality of life and family functioning. *Research in Developmental Disabilities*, 59, 359-369. <https://doi.org/10.1016/j.ridd.2016.09.014>
- Miclea, M. (1997). *Stres și apărare psihică*. [Stress and psychological defense]. Cluj-Napoca: Universitară Clujeană Press.
- Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioral problems and coping strategies. *Frontiers in Psychology*, 10, 464. <https://doi.org/10.3389/fpsyg.2019.00464>
- Noojin, A. B., & Wallander J. L. (1997). Perceived problem solving ability, stress, and coping in mothers of children with physical disabilities: potential cognitive influences on adjustment. *International Journal of Behavioral Medicine*, 4, 415-32.

- Oliveira, E. D. F., & Limongi, S. C. O. (2011). Quality of life of parents/caregivers of children and adolescents with Down syndrome. *Jornal da Sociedade Brasileira de Fonoaudiologia*, 23, 321-327.
- Paster, A., Brandwein, D., & Walsh, J. (2009). A comparison of coping strategies used by parents of children with disabilities and parents of children without disabilities. *Research in Developmental Disabilities*, 30(6), 1337-1342. <https://doi.org/10.1016/j.ridd.2009.05.010>
- Pastor-Cerezuela, G., Fernández-Andrés, M. I., Pérez-Molina, D., & Tijeras-Iborra, A. (2021). Parental stress and resilience in autism spectrum disorder and Down syndrome. *Journal of Family Issues*, 42(1), 3-26. <https://doi.org/10.1177/0192513X20910192>
- Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life outcomes: A qualitative inquiry launching a long-term research program. *Mental Retardation*, 41(5), 313-328.
- Rodrigue, J. R., Morgan, S. B., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of clinical child psychology*, 19(4), 371-379.
- Sadeghi, M., Alipour, A., Abedi, A., & Ghasmi, N. (2013). The effect of life skills training on the life quality of adolescent orphans. *Social Welfare Quarterly*, 13(49), 269-286.
- Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behaviour Therapy*, 19(4), 15-32.
- Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PloS one*, 14(7), 0219888. <https://doi.org/10.1371/journal.pone.0219888>
- Sharpley, C. F., Bitsika V., & Efremidis B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability*, 22, 19-28.
- Smith, L. E., Seltzer M. M., Tager-Flusberg H., Greenberg J. S., & Carter A. S. (2008). A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD. *Journal of Autism and Developmental Disorders* 38, 876-89.
- Stanojević, N., Nenadović, V., Fatić, S., & Stokić, M. (2017). Exploring factors of stress level in parents of children with autistic spectrum disorder. *Specijalna edukacija i rehabilitacija*, 16(4), 445-463. <https://doi.org/10.5937/specedreh16-13861>
- Suls, J., & Fletcher, B. (1985). The relative efficacy of avoidant and nonavoidant coping strategies: a meta-analysis. *Health psychology*, 4(3), 249.
- Tarakeswahr N., & Pargament K. I. (2001) Religious coping in families of children with autism. *Focus on Autism and Other Developmental Disabilities*, 16, 247-60.
- Tomeny, T. S. (2017). Parenting stress as an indirect pathway to mental health concerns among mothers of children with autism spectrum disorder. *Autism*, 21, 907-911. <https://doi.org/10.1177/1362361316655322>
- Verdugo, M. A., Córdoba, L., & Gómez, J. (2005). Spanish adaptation and validation of the Family Quality of Life Survey. *Journal of Intellectual Disability Research*, 49(10), 794-798.
- Woolfson, L. (2004). Family well-being and disabled children: a psychosocial model of disability-related child behaviour problems. *British Journal of Health Psychology*, 9(1), 1-13.
- Yorke, E., Pippa, W., Weston, A., Rafla, M., Charman, T., & Simonoff, E. (2018). The association between emotional and behavioral problems in children with autism spectrum disorder and psychological distress in their parents: a systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 48, 3393-3415. <https://doi.org/10.1007/s10803-018-3605-y>